

Quality of Life in Long-Term Survivors of Intensive Care

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Abstract

Introduction: Traditionally, outcome from intensive care has focused on mortality. The cost of intensive care and the limited resources devoted to patients who have a poor prognosis also raises questions about the utilisation of such resources. There is increasing pressure for outcome evaluation of intensive care to incorporate assessment of long-term survival and the quality of life in survivors. The principal objectives of this article were to examine current methods of assessing quality of life measures in critically ill patients surviving intensive care and to determine the quality of life of these survivors. **Methods:** Direct and computerised search of published research articles. **Results:** Measurement of quality of life after intensive care is not common practice. There is a lack of consensus concerning appropriate measuring instruments to be used and how best to interpret results. Despite the availability of general outcome tools and disease specific instruments, there is a paucity of studies in the literature which include assessments of quality of life following intensive care unit (ICU) care. Generic health indices suggest that the quality of life in ICU survivors is acceptable though in certain sub-groups, e.g. adult respiratory distress syndrome and sepsis, quality of life may be moderately impaired. ICU survivors appear to suffer less disability than chronic physical disease patients. **Conclusions:** Assessment of outcome after intensive care should include health related quality of life measurements. A unifying framework is required to enhance communication between clinicians, administrators and investigators of quality of life research and also to enable more rational and effective decision making at the bedside. Patients who survive intensive care appear to enjoy a reasonable standard of quality of life. While their health status may not be as good, subjectively patients find this acceptable.

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Introduction

Intensive care has undergone rapid technological advancement in recent years enabling complex treatment of patients of advanced age and/or with advanced chronic diseases underlying their acute medical problems. New interventions have been introduced with success determined by their ability to save lives. In-hospital mortality has become an essential quality assurance tool in intensive care.¹⁻⁵

However, the effectiveness of intensive care also involves assessing long-term survival and the quality of life (QOL) in those survivors. Measurement of health related quality of life (HRQOL) after intensive care is not common practice. There are pragmatic difficulties related to obtaining data from patients before admission and following discharge. There is a lack of consensus over the instruments to be used and also how best to interpret the results.

Combined with the limited resources available to intensive care, it has become increasingly important to audit patient outcome carefully. The costs of intensive care are high and

ICU consumes scarce resources. These resources may be devoted to patients with a poor prognosis who may ultimately die. Given this, there is increasing pressure to justify utilisation of intensive care resources. It has become increasingly important to ask what effect does the ICU illness have on long-term QOL? It is recognised that in assessing the effectiveness of treatment in intensive care, it is both survival rates and quality of life which are important.

The objectives of this article were to examine current methods of assessing QOL measures in critically ill patients surviving intensive care and to determine the QOL of these survivors.

Current Methods of Assessing Quality of Life Measures in Critically Ill Patients Surviving Intensive Care

There is a lack of a clear framework for defining and describing quality of life measurement following intensive care. Various terms such as quality of life, health status,

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functional status and HRQOL have been used interchangeably in the literature without a precise definition being applied. Because the language has not been standardised, it has created difficulties both in assessing the different methods used in quality of life assessment and also in making direct comparisons between studies.

Definition of Quality of Life

QOL can be defined as the “well being” of an individual. Well-being is determined by several factors: health status, social relationships, employment status, the well being of others, etc. Health status measurements assess physical, physiologic and psychological states or function. Aspects of health status that people value overlap with components of QOL and these can be referred to as health-related quality of life (HRQOL).

How is HRQOL Measured

Previous discussions have described the key measurement properties of HRQOL and the available strategies for measuring HRQOL.^{6,7} These describe the two principal goals of a HRQOL measurement tool as being able to differentiate between those who have a better HRQOL from those who do not (discriminative tool) and also the measurement of the degree to which HRQOL has changed (evaluative tool). Several factors describe what makes a good measurement tool.

Signal and Noise: As the signal of a measurement tool increases and the associated noise decreases, its usefulness correspondingly increases. **Reliability** describes the quantification of the signal/noise ratio for a discriminative tool. If the signal, i.e. the variability of scores between patients is much greater than the noise, i.e. the variability within patients, then the measurement tool is reliable. If every one essentially gets the same score (low signal), then the discriminative value of the tool is low. Likewise, if there is a wide variation in the patient’s scores (high noise), little can be said about the patient’s relative well being. For evaluative tools, the way of determining the signal/noise ratio is called **responsiveness**, which allows us to measure changes within patients over time. Responsiveness refers to a tool’s ability to detect change and is directly related to the magnitude of the difference in score in patients who have improved or deteriorated (the signal) and the extent to which patients who have not changed obtain more or less the same scores (the noise). An unresponsive tool may result in a false negative trial in which the intervention improves how patients feel, but which is not detected.

Validity: This describes the extent to which an outcome measure measures what it is intended to measure. **Construct validity** is the most vigorous attempt to establish validity. It is a process whereby the measure is correlated with

preconceived differences, which may be clinically established or theoretical constructs. By understanding the construct, expectations are then developed as to how a tool should behave if it is valid. For example, is there a relationship between exercise capacity and dyspnoea such that we could expect those patients with greater exercise capacity to exhibit less dyspnoea? For a discriminative tool, construct validity is established by examining cross-sectional correlations between the tool under study and other measures. For an evaluative tool, construct validity is established by showing that changes in the tool correlate with changes in other related measures.

Interpretability: A discriminative tool determines whether a patient is functioning normally or has mild, moderate or severe disability while an evaluative tool would determine whether a change in score represented a trivial, small, moderate or severe improvement or deterioration.

HRQOL Tools: There are two basic approaches to describing HRQOL tools – generic and specific. Generic tools attempt to measure all important aspects of HRQOL. Several have been used in critically ill patients, including the Sickness Impact Profile,⁸⁻¹⁰ and the Short-Form 36.^{11,12} Differences in the choice of measurements to evaluate HRQOL mean that comparisons between different studies are difficult. Some of these general tools¹³ concentrate largely on functional status and do not measure a patient’s subjective satisfaction. Others (SF-36) include a subjective assessment by the patients of their health. In addition, there are practical difficulties in completing a HRQOL questionnaire when fatigue, poor concentration and physical disability may be features. The advantages of generic tools are that many areas can be examined and that they can be applied to a broad spectrum of populations, for example an ICU population. The disadvantage of such tools, however, is that they are less responsive to changes in specific disease states. Specific tools, on the other hand, focus on aspects of health status that are specific for a disease state or symptom. This encourages increased responsiveness by examining only important aspects of HRQOL relevant to the disease state or symptom being studied. The disadvantages of a specific tool are that comparisons cannot be made across conditions and unexpected side effects may be missed during evaluation.

More limited questionnaires have concentrated on the patient’s subjective perception of QOL. Several studies that have utilised a generic tool for assessing HRQOL also include a questionnaire for a patient’s subjective evaluation, e.g. Quality of Life Index.⁸ Other clinical studies use simple systems for the evaluation, with concentration on functional dependence but without the subjective analysis.¹⁴

Despite the availability of models for assessing HRQOL, there is a paucity of studies in the literature which include

assessments of QOL following ICU care. Heyland et al⁷ carried out a computerised bibliographic search of published research and a manual search of three key intensive care journals. Less than 2% of articles involving adult intensive care included QOL measures. They found 64 journal articles that met their criteria that reported on patient-related outcomes other than mortality after hospital discharge. These papers dealt primarily with issues of prognosis [32 (50%)], resource allocation [23 (36%)], and clinical prediction [9 (14%)]. No randomised trials were found that included post-ICU QOL as an outcome. In the 64 studies, 108 different instruments were used and few reported on their reliability and validity. Furthermore, the authors concluded that HRQOL ideally should have been reported in 60% of papers which measured morbidity and mortality in critically ill patients.

Quality of Life in Critically Ill Patients Surviving Intensive Care

Sickness Impact Profile (SIP)

The Sickness Impact Profile (SIP)¹³ is a multidimensional generic health index that evaluates all areas of sickness-related behaviour. It consists of 136 yes/no type questions divided into twelve categories. It provides an absolute measure of functional health status and is appropriate for use when comparing outcomes for different diseases, and does not require a value prior to the illness for its validity in documenting current health status, as is the case for most ICU admissions. It has been extensively validated for use in outcome studies¹⁴ and has been calibrated for use in Hong Kong Chinese.¹⁵

The SIP was designed to enable comparisons among patients with different disabilities and is an absolute measure of health status. Because the importance of the various items in the SIP are weighted by the society in which the

questionnaire is used, it represents a societal judgement on the degree of health-related dysfunction that the patients are suffering. It is not a guide to patients' perceptions of their degree of well-being. Many factors contribute to a patient's perception of his/her state of well-being, and elderly patients are more likely to rate their QOL as satisfactory in the face of apparently severe degrees of health-related dysfunction than young patients.

The SIP has been used as a measure of functional health status in three previous ICU outcome studies (Table I).⁸⁻¹⁰ Comparisons of outcome data with these studies are limited by differences in age, spectrum of diseases, and severity of illness of patients, and differences in admission criteria and response rates for the various studies. The studies by Sage et al⁹ and Tian and Miranda¹⁰ suffered from low response rates of 42% and 58%, respectively. A low response rate increases the likelihood of selection bias in the patients who responded to the survey and, therefore, the severity of health dysfunction reported. In the study by Short et al,⁸ an 85% response rate in hospital survivors in a large patient sample was achieved. There were also considerable differences in age, severity of illness and case mix of patients in three studies.

The study by Sage et al⁹ assessed the survival and QOL in 140 patients 16 to 20 months after discharge from a mixed medical-surgical ICU, and concluded that QOL was good. The total SIP score in this study was significantly less than that recorded in other studies for different populations of patients, suggesting that ICU survivors suffer far less disability than chronic physical (chronic obstructive airways disease, rheumatoid arthritis) or mental (pain, depression) disease patients.⁹ Disability was greatest when relating to home management, work, recreation, sleep and alertness but was less when involving ambulation, mobility, body care, social interaction, communication and

TABLE I: COMPARISONS WITH PAST LONG-TERM ICU OUTCOME STUDIES IN WHICH THE SIP WAS USED AS A MEASURE OF HEALTH STATUS

Author	Patients assessed	Response rate (%)	Assessment at (yr)	Age (mean, yr)	LOS (mean, days)	APACHE II (mean), all patients	In-hospital mortality (%)	Post discharge mortality (%)	APACHE II score (mean), survivors	SIP score (mean), survivors	Method of assessment
Sage (USA) 1986 ⁹	140	42	1.5	58	3.1	15	11	13	13	6.8	Self administered
Tian (Europe) 1995 ¹⁰	3655	58	1	60	2.7	-	-	-	10	8.5	Self administered
Short (HKSAR) 1999 ⁸	853	85	1	47	3.0	18	35	15	14	9.4	Self administered and telephone interview

eating. There were no significant differences between elective surgical and other patients in terms of the SIP constituent scores, physical and psychosocial subscores, nor total SIP score.

The study by Tian and Miranda¹⁰ validated the structure of the SIP in discharged ICU patients and explored the influence of age upon the components of QOL. This was a prospective study in 36 Dutch ICUs in which patients answered an SIP questionnaire 6 months after discharge from hospital. Their results suggested that a patient's QOL was dominated by dysfunction of the physical dimension categories (sleep and rest, house management, eating, body care and movement, mobility and ambulation), except for those between the ages of 30 and 50 years when dysfunction of the psychosocial dimension (emotional behaviour, social interactions, alertness behaviour and communication) was dominant. No correlation was found between SIP and the severity of illness, workload or length of stay in the ICU.

Short et al⁸ assessed the mortality and functional health status of patients 1 year following admission to a multidisciplinary ICU in Hong Kong. Prospective data from 2268 consecutive patients admitted over a 2.5-year period were analysed, including a follow-up of 853 adult survivors. Comparisons between survivors and non-survivors at 1 year found survivors to be significantly younger, more likely to be female, more likely to have had an operation and to have lower APACHE II scores. Patients with haematologic, neurologic or metabolic primary system failure were more likely to survive to 1 year. Patients admitted with primary precipitating factors such as intracranial haemorrhage, trauma or neoplasm were also more likely to survive to 1 year. Analysis of the SIP scores as a measure of functional health status at 1 year post-admission found 30% of patients with an SIP score of 0, 21% an SIP score of 1-5 and 25% an SIP score of 6-15. The remaining 24% of patients had more severe degrees of health disability. Among survivors, 3.6% of patients reported having retired for health-related reasons and a further 1.7% were not working for health-related reasons. Among patients aged 16 to 60 years, 3.4% of survivors had retired for health-related reasons and a further 2.6% were not working for health-related reasons. Significant factors predicting in-hospital death for adult patients included cardiac or respiratory arrest, neoplasm, and liver or gall bladder disease. Age and length of ICU stay did not predict mortality per se. There were virtually no vascular or cardiovascular patients. In common with other studies, Short et al⁸ found a trend of higher SIP scores with increasing age, poor previous health status and high APACHE II scores. However, no factors were identified as having a particular predictive accuracy. Many patients with high APACHE II

scores had low SIP scores and vice-versa.

Patients who could not be traced were significantly younger, more likely to be male and more likely to be non-operative than those who could be traced. Because there was an association between age and a poor outcome, it was possible that Short et al over-estimated the degree of loss of functional health status in survivors. However, the confounding problem of not being able to trace patients who had either died or moved house because of disability related to their illness would probably balance this out.

Short Form 36 (SF-36)

The Short-Form 36 originated from the United States in the 1990s.^{11,12} It is a self-completed questionnaire which covers all aspects of health-related QOL. It contains questions on functional status, emotional and social well-being, and overall evaluation of health. It contains 36 questions which are summarised into 8 categories: physical functioning, social functioning, role limitations caused by physical problems, role limitations caused by emotional problems, mental health, energy and vitality pain and general perception of health. Low scores on the SF-36 reflect poorer health. The validity and reliability of the SF-36 have been confirmed.^{11,12,16,17}

Eddleston et al¹⁸ assessed survival, morbidity (physical and psychological) QOL and employment status of 143 intensive care survivors up to 12 months after discharge from the ICU. The SF-36 was used to assess HRQOL 3 months after discharge from ICU. At 3 months, 80% of all patients interviewed were satisfied with their QOL and there was a low incidence of ICU-related psychological or psychiatric illness. The scores on all domains of the SF-36 were numerically much lower than the published scores for the general population, with the exception of mental health. Younger men, those aged <65 years, had significantly worse health in some domains than their older counterparts: role limitation caused by both physical and emotional incapacity and social functioning. In contrast, women aged less than 65 years had better function in the domains related to emotional statistics and physical functioning than those older than 65 years. Older women scored better for mental health. While scores at 3 months were generally lower when compared to the general population, the vast majority of patients were satisfied with their recovery. These results are similar to those of Ridley et al,¹⁹ who examined changes in QOL 6 months after discharge from ICU. They documented significant increases in the domains of mental health, vitality and social functioning and a reduction in pain scores at 6 months post ICU.

Davidson et al²⁰ examined HRQOL in survivors of acute respiratory syndrome (ARDS). Their results indicated clinically and statistically significant reductions in HRQOL

scores in 7 of 8 SF-36 domains that appeared to be caused exclusively by ARDS and its sequelae. The reductions were primarily in the physical functioning and pulmonary disease-specific domains. Similar findings have been documented in patients with acute lung injury.²¹ HRQOL and post-traumatic stress disorder in survivors of ARDS had been examined by Schelling et al²² utilising the SF-36. This retrospective study assessed 80 patients who survived an episode of ARDS. Significant impairment in all health dimensions of the SF-36 occurred when compared to normal controls. There was impairment in physical function (25% reduction), physical role function (50% reduction), general health (15% reduction) and there was a much higher incidence of chronic pain. Most survivors, however, perceive a relatively high QOL. Interestingly, patients reporting more than one adverse experience during their stay in ICU had a significantly lower HRQOL than survivors with none or only one adverse experience. Heyland et al²³ evaluated HRQOL in survivors of sepsis utilising the SF-36. Survivors of sepsis scored significantly lower on the physical functioning, physical role, general health vitality and social functioning domains compared with established norms for the USA general population.

The appropriate timing for assessment of HRQOL following discharge from ICU has not been established. Assessments have been carried out at 3 months,¹⁹ 6 months,^{10,19,24} and 12 months,^{8,25} while only a few extended beyond 12 months.^{22,26,27} A limited number of studies have examined HRQOL over time, but both Eddleston et al¹⁸ and Ridley et al¹⁹ reported a natural improvement in HRQOL up to 6 and 12 months respectively following discharge from intensive care.

Subjective Assessment of Quality of Life

Besides generic tools to assess HRQOL, several studies have included a subjective assessment by the patient of his/her HRQOL. Patrick et al²⁸ developed the Perceived Quality of Life Scale, which sums up the level of satisfaction within 11 areas of life. They studied a small group of highly selected, motivated patients, in whom a global assessment of outcome from ICU was not the primary objective of the study. The patients were selected because of their advanced age and the presence of chronic health problems. Patrick et al found that scores of the critically ill elderly patients were similar to a similarly matched group living in the community.

The prospective study by Mata et al²⁹ in a single Spanish ICU consisted of a questionnaire on admission of 444 patients and again 12 months after ICU discharge. The questionnaire measured 7 items that emphasise function and independence. The patient's functional status as measured by the QOL score was influenced most by age and their QOL score at the time of ICU admission. Fifty per

cent of survivors had a worse QOL score. The decrease in score was more evident in those over 75 years. This result was similar to that of Mundt et al,³⁰ but Sage et al⁹ showed that this does not necessarily indicate a worse subjective perception by the patients of their own QOL. Younger patients (<45 years) showed no worsening of QOL. Others have described a more pronounced deterioration in younger patients,³¹ which may be due to a lack of trauma patients in Mata's study. Patients with the highest initial QOL scores showed an improvement in their QOL if they survived ICU. Goldstein et al³² made the same observation.

Short et al⁸ included the QOL Index as a subjective rating scale. This was found to be non-discriminative and not sufficiently accurate to act as a rapid diagnostic tool to replace the SIP. One problem is that this questionnaire was designed to assess patients with major illness and is not suitable for administration to healthy patients, which accounted for approximately half of the patients in Short et al's study.

Conclusion

Survival and QOL assessments are important benchmarks for evaluating the overall results of intensive care. However, assessment of the QOL following intensive care occurs infrequently in the ICU literature. Published studies provide a variety of models to assess HRQOL and comparisons between studies are difficult. A more structured framework would facilitate communication and promote more effective decision-making. It would also provide additional and complementary data to mortality data, which would provide a more complete picture of what happens to critically ill patients following discharge from the ICU.

Several generic instruments both with advantages and disadvantages suggest that long-term outcome from intensive care in terms of health-related quality of health is acceptable. However, assessment of the direct impact of ICU interventions upon the QOL of ICU patients would be desirable.

Most studies lack detailed data on previous health status, but it appears that outcome is dependent on the prognosis of the pathology underlying the acute physiological derangement leading to admission and the chronic health status of the patients. They suggest that admission policies for critically ill patients to ICU should be based on prognosis of the underlying disease process rather than the severity of the acute physiological disturbance leading to the request for admission. Patients who survive intensive care appear to enjoy a reasonable standard of QOL. While their health status may not be as good as the general population, patients find this acceptable. Selected subgroups of patients may have a more marked deterioration in their HRQOL.

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